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AUTHOR	Evans, Theora; Garwick, Ann; Rinehart, Peggy Mann
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ABSTRACT

This document reports on a 1998 conference of some 30 parents, educators, social workers, advocates, physicians, nurses, and social scientists who met to develop an action plan for improving the quality of services and cultural competence of providers of services to children with special health care needs from diverse cultural backgrounds. The conference produced 10 recommendations: (1) build mechanisms to assure true family and community participation in design, implementation, and evaluation of programs and services; (2) develop policies and funding that support family-centered culturally competent care; (3) train families and professionals in collaborative decision-making processes; (4) use educational funds to develop core interdisciplinary curricula for professionals; (5) assure compliance with funding agency guidelines regarding culture and ethnicity; (6) develop needs assessments and satisfaction evaluations with stakeholders and families; (7) develop a system of care that promotes the value of the individual and a sense of belonging; (8) increase the numbers of professionals from underrepresented groups in health care; (9) provide flexibility in funding to meet the individual care needs of families; and (10) develop developmentally appropriate and culturally sensitive models for assessing the child's health and functional status. (DB)

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Action Plan

Improving Care for Children with Special Health Care Needs from Diverse Cultural Backgrounds

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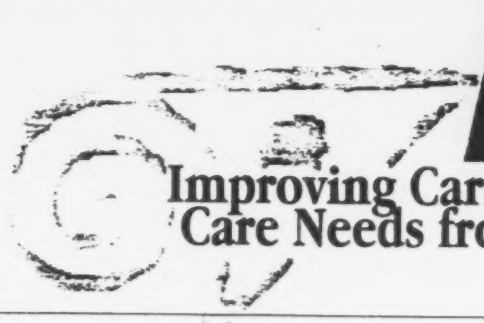

Action Plan

Fall 1999

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EDITOR & DESIGNER
Peggy Mann Rinehart

EDITORIAL ASSISTANT
Elizabeth Latts, MSW

RESEARCHERS
Ann Garwick, PhD, RN
Theora Evans, PhD, MSW

KDWB-VARIETY FAMILY CENTER
University of Minnesota
Division of General Pediatrics and Adolescent Health
Suite 160
University Gateway
200 Oak St.
Minneapolis, MN 55455

Voice: 612.626.2820
Fax: 612.626.2134
E-mail: AHP@tc.umn.edu

Action Plan

Improving Care for Children with Special Health Care Needs from Diverse Cultural Backgrounds

Introduction

BACKGROUND

In June of 1998, some thirty parents, educators, social workers, advocates, physicians, nurses, and social scientists met at Wingspread Conference Center in Racine, Wisconsin, to develop an action plan for improving the care of children with special health care needs (CSHCN) from diverse cultural backgrounds.

This Consensus Conference, ***Children with Special Health Care Needs and their Families: Building on Cultural Strengths,*** built on the work carried out by health care professionals, child and disability advocates, researchers, and parents who participated in the original Wingspread conference on ***Culture and Chronic Illness: Raising Children with Disabling Conditions in a Culturally Diverse World***[1] convened in 1993 and three subsequent ethnic-specific ***Building on Cultural Strengths*** conferences funded by the Maternal and Child Health Bureau. The ethnic-specific conferences held between 1995 and 1997 addressed issues of culture, ethnicity, and access to health care services in American Indian / Alaskan Native, Hispanic/Latino and Black/African American communities. The central goal of the conference series was to improve the quality of services and cultural competence of health care professionals and other providers who serve CSHCN and their families.

The aim of the 1998 Consensus Building Conference was to identify core recommendations for improving care for children with special health care needs from diverse cultural backgrounds and to formulate strategies for implementing these recommendations. A cross-section of representatives, including parents, health care professionals, researchers and steering committee members who had participated in at least one of the ethnic-specific conferences, were invited to attend the Consensus Building Conference. In preparation for the conference, each participant received a summary of the recommendations developed at each of the three ethnic-specific conferences.

[1] Patterson, J. & Blum, R.W. (1993). A conference on culture and chronic illness in childhood: Conference summary. *Pediatrics. 91*(5 Pt. 2) 1025-1030.

METHODS

A nominal group process[2] was used to identify and prioritize core, overarching recommendations for improving care for CSHCN from diverse cultural backgrounds.

The nominal group session was conducted in four phases. First, each participant identified an individual list of high priority recommendations. Next, a collective list of recommendations was generated as participants shared their highest priority recommendations, one at a time, in a round-robin fashion. Then, the compiled list of 41 recommendations was reviewed by the group.

This structured group process allowed each participant to have an equal voice in determining priority recommendations.

Also, the nominal group process fostered consensus-building as participants worked together to prioritize recommendations. Finally, each participant identified and rank-ordered their top five recommendations. Written ballots were collected and tallied. The action plan was based on the top ten recommendations.

Subsequently, participants were divided into three small work groups to develop strategies for implementing the top ten recommendations. Work groups focused on policy, service delivery and training implications in their deliberations. After the conference, each participant received a summary of the core recommendations and action plan to review and critique. The following action plan reflects the collective work and wisdom of parents, policymakers, and health and education professionals who worked together to develop this agenda for providing more culturally competent, family-centered, and community based care to CSHCN and their families.

[2] Delbecq, A.L. (1986). *Group techniques for program planning: A guide to nominal group and Delphi processes.* Middleton, WI: Green Briar.

CULTURAL COMPETENCE...

"THE ABILITY TO HONOR AND RESPECT A FAMILY'S BELIEFS, INTERPERSONAL STYLES, ATTITUDES AND BEHAVIORS, AS WELL AS TO EMPLOY MULTICULTURAL STAFF TO PROVIDE SERVICES."

TOP TEN RECOMMENDATIONS

1. Build mechanisms to assure true family and community participation in the design, implementation and evaluation of programs and services.
2. Develop policies and funding that support family-centered, culturally-competent care.
3. Train families and professionals in collaborative decision-making processes in the best interest of the child.
4. Use educational funds to develop core interdisciplinary curricula for professionals.
5. Assure compliance with funding agency guidelines regarding culture and ethnicity.
6. Develop needs assessments and satisfaction evaluations with stakeholders and families.
7. Develop a system of care that promotes the value of the individual and a sense of belonging, thereby eliminating alienation.
8. Increase the numbers of professionals from underrepresented groups in health care.
9. Provide flexibility in funding to meet the individual care needs of children and their families.
10. Develop developmentally-appropriate and culturally-sensitive models for assessing the child's health and functional status.

MINORITY ACCESS

Most scholars agree: Poor children and youth are more likely to have severe chronic physical conditions than their non-poor peers. And while there is some disagreement, most agree that poor minority children are more adversely affected than their white peers.

Not only are poor minority children more likely to have chronic illnesses or disabilities, school records and teacher reports suggest that minority children are more likely to be categorized as "children with special health care needs." Poor children from culturally and linguistically diverse backgrounds:

- Are more likely to use fewer outpatient services;
- Have more hospital admissions;
- Are significantly less likely to receive medication for their chronic conditions; and
- Use fewer health resources.

Access to, and the use of, health care services are traditionally linked to health insurance. However, even when they have health insurance, the families of poor minority children seek health care significantly less frequently than their non-poor white peers.

For many families of diverse heritage who have children with special needs, the "Western" health care delivery system is narrow in its perspective. These families who have not fully embraced the Western practice of medicine say that a lack of cultural competence is a barrier to health services. This failure to address cultural differences affects the physical, social and emotional functioning of minority children with special health care needs.

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Developing a Model of Care

LISTENING TO FAMILIES

Time and time again, families from racially, ethnically or linguistically diverse backgrounds say they are untrusting of the impersonal nature of many health care environments.

Using the recommendations as a springboard, conference participants declared that a model of care that was more inclusive would contain the following:

- Grounding and access in the community;
- A holistic health orientation;
- Respect for the central role of the family;
- Reliance on a strengths-based perspective (not solely health problems);
- Cultural competence; and
- A focus on resilience.

Conference participants noted that these elements support the interactions and transactions between and among the family, the child, and the health care professionals. These elements have been identified in numerous publications as key factors in linking systems of care for children with special health care needs. What makes this model unique is the fact that families of diverse ethnocultural and linguistic backgrounds have worked with professionals to construct it.

COMMUNITY

Families are saying that, by its very nature, "community" is neither solely geographic nor soley race or ethnic-specific. For our purpose, community is defined as individuals who have a vested interest in the delivery and receipt of health care services for children with special health care needs.

"It's not the programs that make a difference," families and professional are saying. Indeed, lack of trust and connection to the community were frequently mentioned as barriers to services. Investing in community means investing in social capital by developing:

- A vision and language of common good by building bridges;
- A shared view of goals and outcomes in which each member is considered an equal and valued constituent;
- Social trust which allows members to feel connected; and
- Civic engagement, the energy and desire to be involved.

Once both a community's allegiance and needs have emerged, the community can take responsibility for identifying funding sources, developing collaborations and advocating for social, health, and mental health policy formulation.

Such a community promotes and facilitates

open discussion of issues that affect families involved in raising children with special health care needs.

HEALTH ORIENTATION

Families want to be involved in all aspects of their children's care. They want to receive their health care in an environment that respects not only its clients and their families, but also its staff and administrators. Families and practitioners cannot be adversaries. They need to move from a "me vs. them" style of care to one that respects all aspects of a family's life as valuable and life affirming.

"FAMILIES WANT TO BE INVOLVED IN ALL ASPECTS OF THEIR CHILDREN'S CARE."

FAMILY CENTEREDNESS

Family are their own best advocates, yet beliefs around how to behave as an advocate may differ from community to community and culture to culture. Being "family-centered" begins with listening. Facilities that incorporate the value of keeping families at the center of their work are likely to understand just what's happening in daily family life that affects the lives of the children they see. They understand and can address issues such as unemployment, maternal poor health and financial burdens.

When providers respect families, they are more likely to receive clear and unbiased feedback from family members that, in turn, allows them to understand and treat the needs of the child with special health care needs more effectively.

INDIVIDUAL STRENGTHS

Often, those who are in a racial, ethnic or linguistic minority feel marginalized by the institutions that are supposed to provide them with health care. In these cases, providers seem to "blame" their child's health on the circumstances of their family's living: poverty, different nutritional views, religious differences, poor understanding of English, to name a few.

Conference participants want providers who look for the strengths in the families and children they see. Such providers are non-blaming, solution-focused, and able to capture the strengths of a variety of perspectives. The ideal health system addresses the physical and emotional needs of its community and recognizes the importance of spiritual health. Acknowledging spirituality permits health providers and families to seek common ground in expressing their humanity and comprehending cultural differences in decision-making.

Clinics and hospitals need to be tolerant of spiritual expression, and providers need to be comfortable with addressing social, emotional and physical functioning.

CULTURAL COMPETENCE

All conference participants recognized that "cultural competence" is a dynamic— an ever evolving process. A culturally competent system, then, is ever vigilant of its policies, funding strategies and guidelines.

A culturally competent individual is capable of understanding and respecting multiple perspectives. A culturally competent person can, quite literally, walk in another's shoes. The provider, then, seeks to complement, adapt, or integrate practice protocols in a culturally appropriate way.

A culturally competent organization values and nurtures cultural competence in everything it does. It evaluates and reevaluates its capacity to deliver services and achieve outcomes that both its providers and clients want.

"A CULTURALLY COMPETENT PROVIDER ACTIVELY LISTENS TO THE FAMILY AND COMMUNITY MEMBERS."

Providers who acknowledge and accept the concept of cultural difference also realize that, while most values are universal, the way those values are translated into everyday activities may be very different.

A family may want and need to seek the advice of many different professionals when raising a child with special health care needs. These professionals may include a Western trained physician, a native healer, or another religious leader. Each may provide conflicting advice. A family that chooses not to take the advice of a Western trained physician chooses what they believe to be the best advice based on their understanding of the world.

RESILIENCE

A system that values resilience expects families to "bounce back after facing and coping with adversity" and helps families find that resilience in every interaction. Conference participants ask that policymakers, administrators, funders, advocates, health and service providers, parents and families work together to minimize the risk of poor health outcomes for underserved minority families who have children with special health care needs. All adults, whether providing direct or indirect resources, should be aware of their capacity to positively affect the physical and emotional well-being of children and youth in their care.

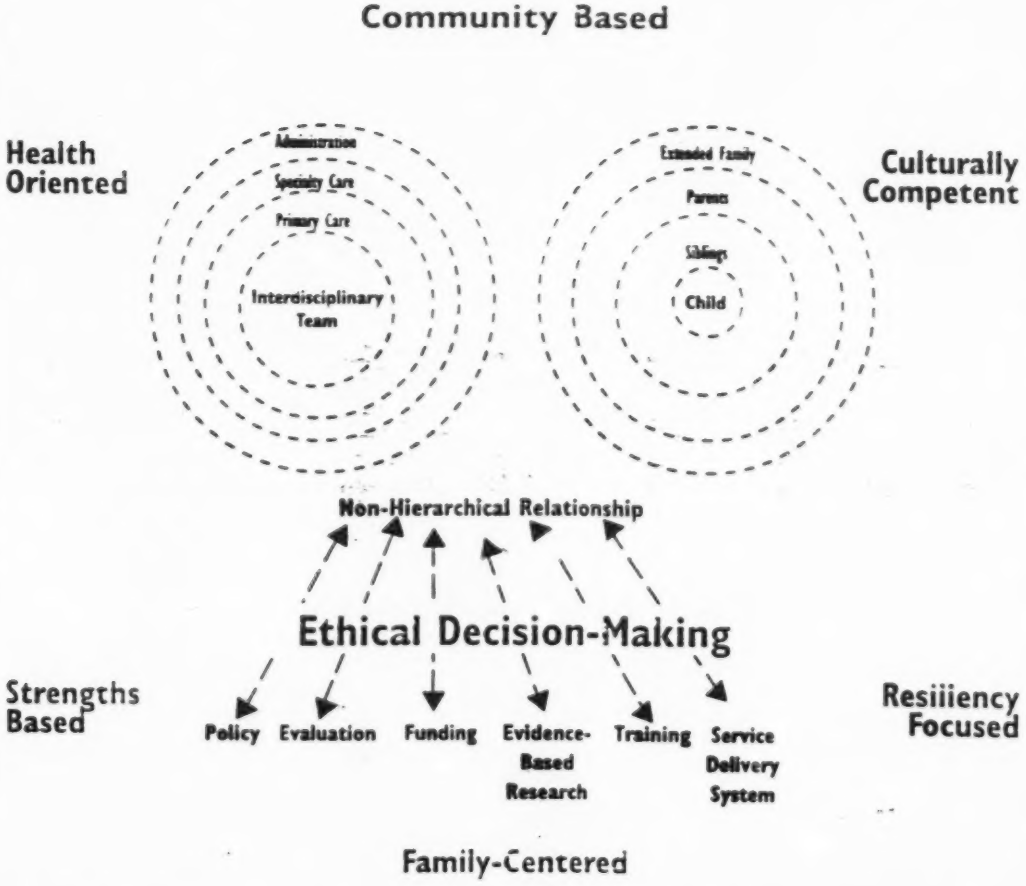
Every element within the model needs to be people-driven, therefore each person also has an obligation to nurture others. In this model of care, there are no victims to blame. There is only

the capacity to look inward and alter anything that is seen as a barrier to quality service.

Many minorities are saying that models of care based on dominant society members may not always be applicable to them. Social and health care systems are being asked to become nonlinear, non-hierarchical systems in order to address the diverse needs of people in American society today. Models of care must understand the impact they have on those who do not share the social and cultural norms of the majority population.

Conference participants ask administrators, funders, and providers to examine the ethical principles of their various professions. The systematic change necessary to activate a more egalitarian model of care may be more philosophical than structural.

Model of Care for Children with Special Health Care Needs



Making the Ideas a Reality

Participants attending the Children with Special Health Care Needs and their Families: Building on Cultural Strengths conference on June 27, 1998, agreed on the top 10 priorities for developing culturally competent health care services. Here are their suggestions for implementation.

RECOMMENDATION #1:

Build mechanisms to assure true family and community participation in the design, implementation, and evaluation of services and programs.

1. Include families in the design, implementation and evaluation of programs and services provided to them.

Heads of key federal and state agencies that fund services should require family and community participation in the design, implementation, and evaluation of these services.

Providers need to ensure that parents and youth are at the decision-making tables where issues that affect their lives are discussed. Training materials and agency guidelines need to specifically address how youth and families can be involved in various aspects of programs and services. Family representatives should be involved in developing these training materials and policies. Build on existing parent training resources and link with parent training organizations such as *Family Voices*, *Parents as Teachers* and *Partners in Policymaking* known to provide leadership training opportunities for children, families and youth. Evaluation data on the costs and benefits of including parents as advocates and educators in programs are needed to support their continued involvement.

Family representatives should be people who can represent other families and their needs. Furthermore, representatives should have active, not token roles, in planning services and programs.

Provide support systems for parents who are in paid or ongoing volunteer positions in programs. Investing in family representatives reflects the value that parents have in the system and increases the likelihood that parents will stay actively involved in the program.

2. Improve the delivery of services to enhance participation.

Strategies for improving the delivery of services include:

- Developing referral systems that serve the needs of families;
- Coordinating and integrating different systems of care;
- Promoting interagency collaboration;
- Involving families in the evaluation of services and programs; and
- Training cultural liaisons or community health workers to work in unserved or underserved communities to build bridges between families and services. The liaison could be a family member, a community member or a trained paraprofessional. The goal of the liaison is to help families and communities identify their needs and link them to appropriate services.

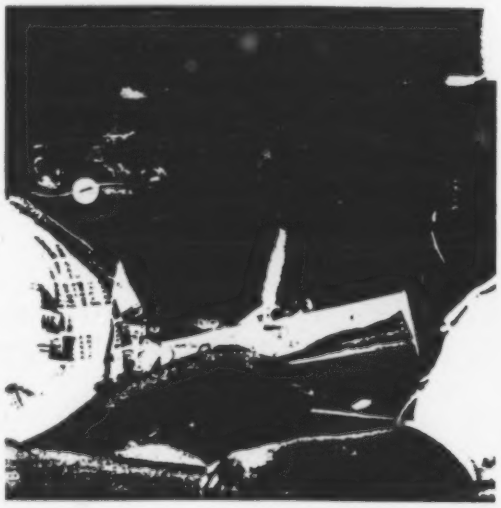
3. Enhance cultural competence in organizations.

Involve key cultural informants from the community, who understand the beliefs and health practices of community members, in planning services and programs. Health care professionals need to know how to identify and incorporate traditional cultural and Western beliefs into healing practices and into health care service delivery strategies. Agencies need to examine policies, assess hiring practices, evaluate

programs, revisit their organizational mission statements and provide staff development to ensure cultural competence within the organization.

4. Build family and community partnerships.

Involve funders, policymakers and program developers in designing family-centered, flexible programs that reflect the norms of the community in all aspects of health care from training to practice and program evaluation and research. Recruit people from the community, especially the disability community, to work in programs and serve as resources in problem-solving activities. Best practices that have been developed through community partnerships need to be identified, evaluated and disseminated, so they can be replicated in other settings. Involve families and communities in the design, implementation, evaluation and dissemination of projects using participatory action research models.



"INCLUDE FAMILIES AND COMMUNITIES IN ALL ASPECTS OF CARE."

RECOMMENDATION #2

Develop policies and funding that support culturally competent, family-centered care.

Policies should be reviewed, and revised if necessary, to ensure that care is indeed family-centered and culturally competent. Professional training programs and licensure boards must include curriculum or content regarding cultural competence, family/provider relationships and ethical decision-making. Include skilled parent representatives on licensing boards who are effective in lobbying and advocating for children with special health care needs. Incorporate cultural competency training into continuing education requirements for professional licensure renewal.

Agencies and programs must operationalize family-centered, culturally competent care which means enacting the following nine elements of family-centered care articulated by the Association for the Care of Children's Health:

- Recognize that the family is the constant in the child's life;
- Facilitate parent/professional collaboration in all aspects of health care;
- Honor the racial, ethnic, cultural and socioeconomic diversity of families;
- Recognize family strengths and respect different methods of coping;
- Inform the family about the child's care in an appropriate and supportive manner;
- Encourage and facilitate family-to-family support and networking;
- Understand and incorporate the developmental needs of children and their families into health care delivery systems;

● Implement comprehensive policies and programs that meet the needs of families; and
● Design health care delivery systems that are feasible, accessible, and responsive to family needs.[3]

Information about "best practices" in this area should be collected, evaluated and disseminated to the public as well as the private sector.

Policies need to support families to be the "best" they can be. Before developing new policies and services, existing resources, gaps, and myths need to be investigated. Understanding the history of previous or current policies, funding criteria, and programmatic regulations is requisite to developing new policies and resources that meet families' needs.

RECOMMENDATION #3

Train families and professionals in collaborative decision-making processes for the best interests of the child.

Health care professionals and policymakers should be provided with information about the benefits of family education and working in partnership with families. Stakeholders need to know how this collaborative process has been successfully implemented and maintained in other programs or initiatives. Discussions between families, professionals, and policymakers need to occur at multiple levels, including national, community, agency, and individual family levels. Such collaborative efforts can accomplish effective systems changes that enhance the quality of care for children with special needs. Ongoing funding mechanisms are required to support these collaborative efforts and training activities for families and professionals.

Policies and expectations must be family-friendly and account for variations in family structures, routines, cultural beliefs and practices. Many professionals and policy makers may need to broaden their understanding of how various people view authority and enter into decision-making. Since perceptions of disability and special health care needs vary considerably, there is also a need for providers and families to identify and discuss how these perceptions influence the child's care.

Professional training needs to include skill building (e.g., how to listen to families, how to collaborate with families in managing the condition) and knowledge acquisition (e.g., the impact of the chronic condition on the family, the benefits of providing family-centered care in terms of treatment adherence and family satisfaction).

Students and professionals also need training in how to work collaboratively with families, other professionals, and communities. Strategies for developing community-based programs and interventions experiences should be included in the curricula.

Family training needs to:
● Build on existing resources and state-of-the-art training programs that are culturally competent.

Recognize the developmental stages of family education and provide support and appropriate training along a continuum. Resource information for children with special health care needs and their families needs to be available in a wide range of settings, such as clinics, schools, community centers, retail stores and libraries. Also, orientation sessions and informational materials should be developed to help families navigate systems of care. Families also need to know how to advocate for their children and form partnerships with allies to strengthen their

[3] Shelton, T.L. & Stepanek, J.S. (1994). *Family centered care for children needing specialized health and developmental services.* Association for the Care of Children's Health, PO Box 25707, Alexandria, VA 22313, 1-800-808-ACCH.

"TRAIN FAMILIES & PROFESSIONALS TO COLLABORATE."

advocacy efforts.

Training programs need to account for the particular learning needs of the participants. Although a number of effective parent training programs have been developed, accessibility is limited by factors such as time, motivation, availability, language, location, and literacy. Quality programs need to be identified and evaluated so that information about state-of the-art programs can be disseminated and made available to a larger number of families.

- Involve parents in training professionals.

In terms of recruitment, develop a systematic way of identifying numerous families from diverse backgrounds to partner with as trainers rather than repeatedly relying on the same families. Developing a broad base of family trainers prevents parent " burn out" and ensures that diverse family viewpoints are represented. Recruit parents by linking with existing community-based programs that know families and the needs of the community. Within your area, develop a Speakers Bureau that lists parents' expertise and contact information

- Provide training and ongoing support for parent educators.

Include information and skills that parent educators will need to effectively train professionals in their setting. Identify the supports that families need to stay involved in training such as funding, parking, and child care.

"DEVELOP INTERDISCIPLINARY CURRICULA FOR PROFESSIONALS."

RECOMMENDATION #4

Use educational funds to develop core interdisciplinary curricula for professionals.

The interdisciplinary nature of services for children with special health care needs calls for professionals and policy makers who have expertise in working collaboratively and in interdisciplinary teams. Interdisciplinary training is based on the premise that professionals who work with CSHCN and their families require a common set of knowledge and skills. As students from various disciplines work and learn together, they also gain essential collaborative skills and knowledge about other disciplines. Professional training programs need to define what constitutes interdisciplinary versus discipline-specific training (i.e., psychological evaluations) and expertise. Utilize existing resources, such as federally funded interdisciplinary disabilities studies training programs, to accomplish this recommendation. A centralized repository of information on interdisciplinary programs needs to be established.

Cultural competence is a critical component to incorporate into interdisciplinary training programs. Training programs need to ensure that professionals have the values, attributes, skills and knowledge base to work effectively within and across cultural groups and to understand how culture influences the care of CSCHN. Professionals need to be aware of their own cultural background, beliefs and biases as well as the cultural heritage of the children and families they serve. Cultural competence training needs to be included in pre and post professional training programs, and continuing education opportunities need to be available for practitioners, administrators, and policymakers.

Two major components of cultural competence training include interpersonal process and population-based issues. In terms of skills, practitioners need to be effective communicators and listeners in order to provide care that is culturally competent. They also need to beware of cultural stereotypes and be knowledgeable about within group differences.

Core universal standards related to cultural competence need to be identified for health care professionals. These standards and practice guidelines should be based on scientific evidence and expert input. Universal standards would provide guidelines for training programs and professional licensing criteria and examinations.

RECOMMENDATION #5:

Assure compliance with funding agency guidelines regarding culture and ethnicity.

Tie funding to real, demonstrable outcomes of family-centered, culturally competent care. There is a need to build in true accountability for funded programs that profess to be "family-centered" and "culturally competent." Sometimes programs use the appropriate terms to get funded, but do not follow through or have the skills to enact this type of care. Once funded, programs need to be evaluated to determine whether they are, in fact, providing family-centered care. Families need to be involved in measuring outcomes. Culturally competent, family-centered, and community-based components of MCHB Block Grants also need to be evaluated and enforced. Training opportunities and technical assistance should be available for programs that have difficulty implementing family-centered care.

RECOMMENDATION #6

Develop needs assessments and satisfaction evaluations with stakeholders and families.

Data collection should focus on elements that represent the values and concerns of the payors, families, agencies and recipients of care. To accomplish this goal, heads of key federal and state agencies should require community participation in the design, implementation, data collection, and evaluation of funded services. Policymakers need to assure flexibility and continuity of data collection activities in a variety of areas that affect child health, including housing, utilities, support networks, transportation, environment, day care and social services.

Needs assessments and consumer evaluations provide critical information that professionals and organizations can use to ensure the relevance and quality of services and programs to families and communities. Feedback mechanisms, such as customer and family satisfaction surveys, need to be developed to determine which services and programs work well for children and their families.

Evaluation data can be used to shape and reshape programs and services to meet family and community needs. For example, family satisfaction surveys should determine whether family concerns have been met. Parents need to know the process by which they can provide feedback to a provider or agency. Mechanisms for ongoing evaluation and feedback are needed to ensure that program goals are met.

RECOMMENDATION #7

Develop a system of care that promotes the value of the individual and a sense of belonging, thereby eliminating alienation.

To operationalize this recommendation, social/interpersonal and attitudinal issues need to be addressed. Social/interpersonal issues relate to how people are acculturated to view persons who are racially, ethnically or culturally different from themselves, which can contribute to biases and prejudices. Social/interpersonal issues include the

"PROMOTE THE VALUE OF THE INDIVIDUAL AND A SENSE OF BELONGING."

language used in assessments, family support groups, respite care, information about services, increasing the number of minority providers who work with CSHCN, recreational programs, cross-cultural skills development, and sensitivity training groups for children and youth with parallel opportunities for parents. Attitudes and lack of knowledge about disability, oppression and discrimination need to be addressed in community education, staff development and training, early intervention training as well as in various child care settings.

To reduce alienation, information, resources, and services need to be accessible. For example, information about how to access and negotiate service systems needs to be available, particularly in underserved rural and inner city areas. Comprehensive services, including access to pediatric specialists and information for families about their choices, should be provided along with information about consumers' rights and responsibilities. Assure that participatory plans of care are in place for families upon discharge from the hospital and that care coordination services are available to serve families. Ensure that families are included in discussions and decisions that affect them. Practice inclusion and acceptance in all aspects of service provision.

Seek opportunities for learning and promoting the strengths of families from diverse cultural backgrounds and ethnic groups. Ways to increase the family's sense of belonging include building relationships that establish trust and respect. Use feedback from families to make policy changes and increase organizational competency. Involve executive, ancillary, and professional staff in developing a culturally competent work place and creating and monitoring organizational change.

RECOMMENDATION #8

Increase the numbers of professionals from underrepresented groups in health care.

Individuals, professional organizations, health care organizations and policy makers need to work together to accomplish this goal. The goal of increasing the representation of persons from underrepresented groups needs to be integrated into every level of the organization or program. For example, professional organizations (e.g., American Medical Association, American Nursing Association, and American Academy of Pediatrics) can help increase the number of professionals from minority groups through accreditation of training programs, providing training and research opportunities for preprofessionals and professionals of color, and offering technical assistance to training programs.

Recruitment efforts need to begin

early by introducing youth to potential careers in the health care field through publicity and participation in career events at school and the community. Provide community-based mentoring opportunities for potential students as well as professionals-in-training to increase the likelihood of their continued involvement in the health care field.

Recognize that program staff need to reflect the community they serve. The number of professionals and allied health care professionals from underrepresented groups needs to be increased. Provide early and ongoing training opportunities in culturally diverse communities. Build in incentives, such as educational debt-reduction, for trainees who are participating in service projects in community-based settings.

"RECRUIT PROFESSIONALS FROM UNDER-REPRESENTED CULTURAL BACKGROUNDS."

Job opportunities, salaries, and opportunities for advancement and promotion for paraprofessionals and professionals from underrepresented groups must be improved to enhance recruitment and retention. Financial and policy barriers related to membership in professional associations and accessibility of licensure need to be addressed.

Efforts need to be made to recruit and retain professionals who are interested in working with CSHCN and their families. Economic barriers to education need to be reduced. For example, funding to historically black universities, tribal colleges, and other culturally specific educational programs who train health care professionals from underrepresented groups needs to be increased. Include traditional cultural healing practices in the curriculum and identify cultural barriers that hinder student learning.

RECOMMENDATION #9

Provide flexibility in funding to meet the individual care needs of children and their families.

Funding sources need to allow for the individual needs of children with special health care needs and their families. Regulations and policies need to be revised so programs can provide coordinated and continuous services that eliminate duplication of efforts. The adequacy of funding and resources for minority children with special health care needs must be evaluated. For example, the relationship between state and tribal governments needs to be defined so that funding for support services is assured for Native American children with special health care needs. The authors recommend that the term "payer of last resort" be removed from all federal and state health and human services.

Pilot demonstration projects that increase choice and allow parents to buy services or equipment are needed. For example, funds might be used to purchase an air conditioner for a child with asthma, or pay for extra ancillary services not paid for by the school or the health care system. Agencies also need flexibility to administer funds to families to use in emergencies.

Build in checks and balances to protect flexible spending programs against perceptions of abuse of funds by families. Possible strategies include demonstrating the cost savings to funders, assessing and evaluating outcomes, utilization and satisfaction in diverse communities, educating parents and practitioners about responsible decision-making and setting up plans to monitor expenditures.

RECOMMENDATION #10

Develop developmentally-appropriate and culturally-sensitive models for assessing the child's health and functional status.

Few culturally relevant assessment tools for CSHCN exist. Measuring health status should go beyond recording days missed at school. Health status measures need to assess functional health within a cultural, community, and environmental context. "New" morbidities, such as learning disabilities, emotional and behavioral disorders, and family violence that influence the child's health status, also need to be assessed. Both population and individually based health outcome measures that are culturally sensitive and reliable are needed.

Comprehensive, strength-based assessments are recommended. Thorough assessment of the child's functional health requires input from the family and integration of assessments gathered in home, health care and school environments. In addition, the impact of environmental factors, such as family environment, housing, and racism, on child health need to be determined. Quality of life issues for CSHCN need to be assessed so that health care professionals and policymakers can work to improve quality of life and reduce barriers that hinder the child's ability to function.

Conclusion

Conference participants were aware of existing problems and gaps in services for CSHCN; they were also optimistic that concerted and coordinated efforts to change systems of care would significantly improve health outcomes for these children. During the Consensus Building Conference, it became clear that CSHCN from various racial and ethnic groups face a number of common problems that could be systematically addressed through changes in policy, training, and service delivery. This action plan provides a framework for improving the care of CSHCN from diverse cultural backgrounds.

Our challenge is to implement the recommendations and strategies in this action plan which are consistent with the principles of family-centered care and the recent policy statement on culturally effective pediatric care developed by the American Academy of Pediatrics Committee on Pediatric Workforce.[4] The message is clear: improving care for CSHCN requires collaboration. We now invite youth, families, health and education professionals, disability advocates, policymakers, and researchers to join us in distributing and implementing this agenda.

[4] American Academy of Pediatrics: Committee on Pediatric Workforce. (1999). Culturally effective pediatric care: Education and training issues. *Pediatrics,103* (1),167-170.

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Participants

The people listed here participated in the conference, "Children with Special Health Care Needs and Their Families: Building on Cultural Strengths," held at the Wingspread Conference Center, on June 26-28, 1998. We've listed titles and affiliations that were current at the time of the conference.

Javier Aceves
Associate Professor of Pediatrics, University of New Mexico

Chris Arthur
Director of Medical Education
Department of Family Medicine, The University of Mississippi Medical Center

Robert Wm. Blum
Professor and Director
General Pediatrics and Adolescent Health, University of Minnesota

Geraldine Brookins
Vice President for Programs, Youth and Education/Higher Education
W.K. Kellogg Foundation

Clarence Buris
Parent
Washington State Fathers Network

Elena Cohen
Director of Programs
Educational Service, Inc.

Melva T. Covington
Associate Director of Epidemiology
CIGNA Health Care of Tri-State Region

John E. Evans
Executive Director
Centers for Minority Health Initiatives and Cultural Competency

Theora Evans
Assistant Professor
Division of General Pediatrics and Adolescent Health, University of Minnesota

Ann Garwick
Associate Professor
Division of Health Management and Policy, University of Minnesota

Tawara Goode
Project Director
National Center for Cultural Competence, Georgetown University

Martha J. Gorospe
Project Director
Education for Parents of Indian Children with Special Needs
Southwest Communication Resources

Jennie R. Joe
Director
Native American Research and Training Center, The University of Arizona

Harriet Kohen
Center Coordinator
Center for Children with Chronic Illness and Disability, University of Minnesota

Phyllis Landry
Parent Consultant
Children's Special Health Services
New Orleans, LA

Carol Locust
Director of Training
Native American Research and Training Center, The University of Arizona

Fernando S. Mendoza
Associate Professor of Pediatrics, Stanford University School of Medicine

Carmen Ramirez
Parent
Austin, TX

Peggy Mann Rinehart
Director of Communications
Division of General Pediatrics and Adolescent Health, University of Minnesota

Dorcas Santos
Parent
Chicago, IL

R.C. Saravanabbavan
Research Associate/Adjunct Professor, Howard University Research and Training Center

Marty Smith
Executive Director
Institute for Health and Disability, University of Minnesota

Trish Thomas
National Outreach Coordinator
Family Voices

Melvin Wilson
Professor
Department of Psychology, University of Virginia

Ela Yazzie-King
Regional Coordinator
Indian Children's Program

Angela Moten
Wingspread Fellow